

The family and HIV

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Abstract

The impact of HIV and AIDS on the family is described, with particular focus on the situation where the child is the first member of the family to be diagnosed. The results of the social stigma, the effect on relationships together with the global, economic and cultural aspects of the disease make it unique. These issues are discussed and an integrated approach to confidentiality, the provision of services for families and involvement of the community is described.

Introduction

In this country HIV infection has been viewed as a disease that mainly affects specific risk groups such as gay men, injecting drug users (IVDUs) and Africans. However, in the developed as in the developing world HIV is becoming increasingly common among the heterosexual population.^{1,2} Society can no longer afford to marginalise this problem which can affect all men and women and children. Increasingly, we will need to deal with the impact of the disease on families.

The word "family" conveys many different meanings. In developing countries it often incorporates the extended family whereas in the developed world it implies the nuclear family or the family of choice. It has been shown that there is a powerful interactive effect between the family and illness.³ When the illness is HIV or AIDS, this is even more marked because of the particular psychological, economic and social stresses which accompany the diagnosis; in addition, it may affect more than one member of the family. In the short history of AIDS, the focus has been on AIDS and the individual—the white homosexual man, the woman, the infected or orphaned child. Yet AIDS has its most dramatic effect at the family level. This article concentrates principally on the situation where a child is the first member of the family to be diagnosed with HIV. Most commonly, the child has been vertically infected and therefore the mother is also infected.

One of the major and unique problems facing families with HIV infection is the social stigma associated with this infection. This compounds and often dominates the psychological and emotional effects of the disease on the family. Despite public education, society continues to penalise and shun those infected with HIV and, fearing rejection by society, families feel they must keep knowledge of the infection secret from extended family, friends and neighbours. The subsequent isolation puts increasing pressure on relationships within the family at a time when the need for external support and care is at its greatest.

The relative importance of the many psychosocial and economic issues which face the family varies and will depend partly on how the diagnosis of HIV or AIDS comes to light. When the child presenting with symptomatic disease is the first in a family to be diagnosed with HIV, parents, as well as facing the reality of a serious, life threatening disease in their child, also learn that one or both of them might be infected. Initially, parents may wish to focus on the child, especially if he/she is unwell, before they can come to terms with being tested themselves. Many uncertainties exist in the family living with HIV and AIDS including uncertainties about which family members are infected and about the future for those who are infected, as the disease is variable both in its incubation period and periodicity of illness. Furthermore, in the situation where the mother is aware of her own diagnosis before or during pregnancy, there is a fraught period of uncertainty before knowing conclusively whether or not the child is infected. Parents in the meantime are constantly anxious and watchful for signs of early illness in their baby.

If HIV is diagnosed first in one parent, the issue of how and when to tell the partner arises. It may also cause a dilemma for the doctor, who although bound by the code of confidentiality towards the individual, has a responsibility to other family members. The situation requires sensitive discussion with the infected individual to help him or her to talk to both the partner and other family members.

Effect on relationships

HIV and AIDS stresses family relationships. Conflict is a frequent problem in any family where a child is chronically ill.⁴ Such children require a greater level of care which can result in less attention being paid to the physical and emotional needs of other family

members. In addition, when the disease is HIV, dismay at not knowing about previous risk behaviours in a partner, secrecy and lack of communication can exacerbate these problems and dominate relationships.⁵ Issues of guilt and blame may play an important role in the family's reaction to the disease—for example, women infected by their partners may blame them for giving them the disease. Sexual conflicts may also arise where one partner is HIV positive and the other negative.

If a woman discovers her HIV status early in pregnancy, hasty and stressful decisions have to be made about termination. If she continues with the pregnancy, and the child is infected with HIV, she feels guilty for having passed the disease to the child. These feelings and conflicts if unresolved may mean that parents are unable to support each other in coming to terms with their child's diagnosis.

For the family of a child with haemophilia and HIV, guilt is often felt by the parents for administering the infecting Factor VIII.⁶ This may be accompanied by feelings of anger towards groups in society such as gay men and IVDU's who they perceive as having infected their child as well as towards the doctors who prescribed the Factor VIII in the first place.

It is not surprising that many families are or become single parent families—usually mothers with their children. Conflicts surrounding the issue of HIV can result in breakup of the partnership or alternatively one parent may already have died. Coping alone as a single parent with one or more ill children is very stressful particularly in a condition with associated social and emotional isolation and where the parent may also become ill.

Approximately a third of vertically-infected children become ill at a very young age.⁷ Thus for parents, the knowledge that their child has HIV infection may be rapidly followed by the reality that the child is dying. About one third of infected children develop HIV encephalopathy with loss of developmental milestones or spasticity⁸ and watching their child regress is often particularly painful for families. Death of a child with HIV also brings its unique problems; for example, the dead child may have to be placed in a sealed coffin which parents may not be allowed to view, thus denying them the chance to grieve properly.

Siblings of chronically and acutely ill children are often severely affected emotionally. Parents often wish to protect the sibling by not sharing with them the knowledge of the diagnosis of HIV or AIDS in their brother or sister or themselves. However, this may simply embitter the sibling who may be aware that something is happening in the family in which he or she is not involved. Even if a sibling is aware of the diagnosis of HIV the reality of not only losing a brother or sister but perhaps one or both parents also

has to be faced. This reality may have to be faced alone if there is no one outside the immediate family with whom to share the burden. It is little wonder that one study observed that 43% of uninfected siblings showed behavioural problems.⁹

Confidentiality

Who, how, and when to tell both within the family and to outsiders are major considerations for the family living with HIV and often a source of worry and stress. Many parents do not want to burden their children with the knowledge of the child's HIV status at too young an age or when they are still well. They may also fear that their child will disclose the diagnosis to others. Furthermore, although children may perceive at an early age that something is wrong, they quickly see what upsets their parents and do not trespass onto "forbidden territory" by asking questions which might cause distress. Often it is the onset of adolescence and sexual development which prompts parents to tell children of their diagnosis. This is already a difficult time and many adolescents react by feeling denial, resentment and anger that they have been deceived in the past. They are often unable to talk to their parents about intimate and emotional matters and because of the social stigma are also unable to speak to friends or other adults. Furthermore, boys with haemophilia are already having to cope with the reality of having haemophilia; having HIV infection as well is seen as a double punishment.

Who to tell outside the family, such as playgroup leaders, school teachers and sports club coaches raises dilemmas for parents. Although there is no evidence of casual transmission occurring in these settings, many parents are afraid their child may infect others if they cut themselves in the school playground, yet they are more afraid of the social stigma their child will face if the diagnosis is made known. Dilemmas also arise between health professionals about the distinction between confidentiality and secrecy. It is ultimately for the mother to decide who to inform about her and her child's diagnosis. However, if accessible, sympathetic and comprehensive care is to be made available, close collaboration between those involved with the child's care is essential. The question of confidentiality needs to be fully addressed within the team and with the family.

An emerging problem for families with children about to enter primary schools is the question of school health records. If a mother was found to be HIV positive during pregnancy, this information may be written in the child health records. If the child subsequently loses antibody and is not HIV infected, medical information on the mother is then passed on to the school in the child health record. Even if the child is infected, should this information be stated on school health records which may not be kept confidential? Many parents are profoundly

unhappy about this situation, and policies need to be made at Health Authority level to address this possible breach of confidentiality.

Economic effects

On a global level, HIV is a disease increasingly associated with poverty, inner cities, and ethnic minorities.^{10,11} The diagnosis of HIV compounds problems such as single parenting, poverty and drug use.⁵ Whereas most diseases affect mainly the old and the very young, HIV predominantly affects those in the prime of life. In parts of sub-Saharan Africa where the mortality rate is high among breadwinners, survivors are deprived of a firm economic base.¹² Where healthcare has to be paid for, families may spend much of their meagre resources on medical care. In other situations, care of infected individuals is added to the burden of government health and social services.

Uninfected children in the family are greatly affected by the disruption of adult relationships and by the death of parents and siblings. Although in the developing world these children may be absorbed into the extended family, AIDS is overburdening this system. Grandparents who were expecting to be supported in their old age find themselves caring for grandchildren whose parents have died of AIDS.¹³ In many countries without a welfare system, those children who are not taken into the extended family find themselves swelling the number of street children, thus putting themselves at risk of HIV and other diseases.¹⁴

In the developed world orphaned children are even more likely to be left without relatives prepared to care for them. In New York and New Jersey alone, it has been estimated that by 1995, 20,000 orphans will need permanent adoption or temporary foster care.¹⁵ In the UK, the Lothian Health Authority in Scotland has had the most experience of training and preparing foster families to take in children born to HIV positive women. Some of these children (who may or may not be infected themselves) have also been adopted. The issues become complex, however, when attempting to find appropriate foster families for children of different cultural, religious and ethnic backgrounds.

Services for families with HIV

Providing support and services for families with HIV infection requires an understanding of the needs of individual families. A multidisciplinary approach to provide comprehensive medical and psychosocial care and coordination with community and voluntary sector resources is the ideal. In the UK, we are only beginning to understand how best to provide care for children with HIV and their families. As yet, there are only small numbers of infected children in the UK,¹⁶ but they often have complex medical

problems. Until there is more familiarity with their management, some centralisation is required. Collaboration and discussion between obstetricians, paediatricians, genitourinary physicians and other adult physicians as well as with general practitioners, health visitors and social and educational services must occur in order to work out the best way of coordinating care for families with HIV. In addition the wishes of the families must be taken into consideration.¹⁷ Increasingly, there is a need for joint clinics, where parents and children can be seen together and care of the whole family coordinated. Through this form of collaboration, appropriate plans can be made to provide satisfactory solutions for situations such as the care of children if their parents require hospitalisation, and of parents with their children if they are ill at the same time.

In situations where the child is the sickest member of the family there is an argument for child-focused but family-centred care with participation from both paediatric and adult health care workers. If the child is the first member of the family to be diagnosed, parents can meet an adult physician and be counselled and tested at the same clinic as they visit with their child; this would facilitate acceptance of testing for themselves and decrease anxiety about having to go through the whole procedure of visiting a separate institution or clinic. Mothers will attend clinics regularly for their child but may be more likely to ignore their own health needs while focusing on the needs of their child. It is inappropriate for a paediatrician to take on the role of discussing the mother's health or possible future pregnancies, yet mothers often want information about themselves from the paediatrician when they visit with their child. It is important that there are outreach workers to liaise with local Social Services, local treatment centres, GPs and health visitors. As the numbers of families increase, the role of the GP and community team will increase; good liaison between hospital and community with attention to the issue of confidentiality is of great importance.

In developing countries, health care is itself severely affected by the impact of economic recession. Existing health structures are often centralised and inflexible to local needs. Community care and participation is important if individuals are not to be rejected by society and lack of involvement of the local community also encourages people to feel they are immune from risk. Care-givers in the home need to be acknowledged for the expertise they acquire through living and caring for someone with AIDS and family and community resources need to be valued, supported and included in discussions and decision making.

Models of care

Models of care for families with HIV are beginning to

emerge¹⁸⁻²⁰ where the medical, psychological and social needs of families with HIV are addressed by a team of workers who also provide support for each other. These models stress the need for an integrated approach with attention to issues such as confidentiality and flexibility according to the needs of families from different social and cultural backgrounds. In addition, families themselves find they have reserves of strength in the face of the adversity of HIV and if they can overcome the fear of disclosure of their diagnosis, may gain much support from each other. The team should play a role in facilitating this activity.

As we enter the second decade of HIV infection, the reality is one of a pandemic with predominantly heterosexual transmission. In most countries and cultures the family is the major unit of society and it is at the family level that change must be affected, both in the attitude towards those infected and the behavioural change required to stop individuals putting themselves at risk. Such change has been shown to be much more than just the acquisition of knowledge;¹⁹ it requires a fundamental change which includes a new and more cooperative way of thinking and of taking individual responsibility.

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